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~ ANNUAL REPORT ~

South Carolina ALZHEIMER'S DISEASE REGISTRY

2012*

ARNOLD SCHOOL OF PUBLIC HEALTH
UNIVERSITY OF SOUTH CAROLINA
COLUMBIA, SC 29208

*Unless otherwise noted, data included in this report cover the period
January 1, 2010 through December 31, 2010,
the most current period with available and comprehensive data.

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~ Executive Summary ~

The Office for the Study of Aging (OSA) at the Arnold School of Public Health of the University of South Carolina (USC), in cooperation with the South Carolina Department of Health and Human Services (SCDHHS), the SC Department of Mental Health, the USC School of Medicine, and the SC Office of Budget and Control, maintains a statewide **Registry** of SC residents diagnosed with Alzheimer's disease or related disorders.

This report uses the abbreviation **ADRD** to indicate “Alzheimer's disease or related disorders.” The term “related disorders” refers to dementias associated with vascular disease, mixed dementia and with other medical conditions such as Parkinson's disease. Where we refer specifically to “Alzheimer's disease” (**AD**), we limit the analysis to individuals with AD only.

Since January 1, 1988, the Registry has identified 199,279 cases of ADRD. During calendar year 2010, the Registry maintained information on 82,772 individuals alive on January 1, 2010.

~ South Carolina Population Prevalence of ADRD ~

Based on the Registry and 2010 population estimates from the United States Census,

- 11.5% of South Carolinians age 65 or over have ADRD
- 42.7% of South Carolinians age 85 or over have ADRD
- Alzheimer's disease prevalence rates vary notably among SC counties
- African Americans are at notably higher risk of an Alzheimer's disease diagnosis than are non-Hispanic whites. At ages 65 and older, for example, African American South Carolinians are 1.76 times more likely to have ADRD as are non-Hispanic whites

Registry Goals:

- Maintain the most comprehensive and accurate state registry of ADRD in the nation
- Provide disease prevalence estimates to enable better planning for social and medical services
- Identify differences in disease prevalence among demographic groups
- Help those who care for individuals with ADRD
- Foster research into risk factors for ADRD

Registry Overview:

Of South Carolinians with diagnosed ADRD:

- 62% have Alzheimer's disease
- 15% have a dementia due to stroke
- 24% have a dementia related to other chronic conditions
- 30% live in an institution
- 64% are women
- 29% are African American
- 42% of those with AD are 85 years or older

Trends of New Registry Cases:

The number of new cases added to the Registry has increased from 2004-2008 at an average of 2.9% per year. The greatest average yearly increase of 10.5% occurred in the age group of 50-64. These results suggest that, over the 5 year time period, the number of individuals diagnosed with ADRD has been the highest in what is considered a “younger” age group in the ADRD spectrum. This has important implications since the Baby Boomers will not have arrived at the age of 65 until 2011 and this report is based on data through 2008. For more details on these trends and others, see the report featured on page 7.

Other Activities of the OSA:

In addition to maintaining the Registry and conducting research using this valuable state resource, the OSA works to provide South Carolina’s older persons and their families with access to quality, reliable health and long term care service delivery systems. Specifically, OSA’s focus includes the following:

- **Provide education** on ADRD management
- **Develop training** on long term care issues
- **Contribute technical assistance** for programs for older South Carolinians
- **Develop programs** including the SC Vulnerable Adult Guardian ad Litem
- **Help to evaluate** programs for older South Carolinians
- **Conduct research** on aging issues

~ *Acknowledgments* ~

The South Carolina Alzheimer's Disease Registry has developed into one of the nation's most important resources for understanding ADRD. The growth and development of the Registry and the related research program in aging at the Office for the Study of Aging have been due to the support of many individuals and organizations. We particularly want to acknowledge the contribution of:

- The **Arnold School of Public Health** at USC, for core support;
- The **Office of Research and Statistics of the State Budget and Control Board**, for its extensive cooperation in maintaining the Registry;
- The **USC School of Medicine** (Department of Medicine, Division of Geriatrics), for providing collaboration;
- The **SC Department of Mental Health**, for access to data;
- The **SC Department of Health and Human Services**, for core support and access to data;
- The **SC Employee Insurance Program**, for access to data;
- The **SC Department of Health and Environmental Control, Vital Records and Public Health Statistics**; and
- The **Lieutenant Governor's Office, Office on Aging**, for its continued support.

~ *Introduction* ~

Someone in America develops Alzheimer's every 72 seconds; by mid-century someone will develop Alzheimer's every 33 seconds.¹

In 2010, the U.S. Census Bureau estimated that there were 605,660 people 65 years of age and over living in South Carolina, and the state was ranked 26th among other states for the highest percentage of persons aged 65 years and older. Since that time, the elderly population in South Carolina has grown at a rapid rate. In fact, by 2030, the U.S. Census Bureau projects that South Carolina will be home to 1.1 million people ages 65 years and older, potentially propelling South Carolina to a ranking of 15th in the nation for the highest percentage of residents over 65 years of age.¹

Alzheimer's disease and related disorders (ADRD) represent an ever-increasing area of concern for families and the healthcare community. Nationwide, an estimated 5.2 million people in the United States are currently living with Alzheimer's disease. By 2030, this estimate is expected to reach 7.1 million; by 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million to a projected 13.8 million.²

With increasing age as a leading risk factor for Alzheimer's disease, South Carolina's rapidly growing population of persons aged 65 years and older presents a challenge to families, communities and those who plan and deliver services for the state.

ADRD is an umbrella term that encompasses many types of cognitive impairment. The Diagnostic and Statistical Manual of Mental Disorder (Third Edition) (DSM-III-R) defines Alzheimer's disease as an impairment of intellectual abilities such as memory, abstract thinking, judgment, other disturbances of higher cortical functions and behavior and personality change severe enough to interfere significantly with everyday activities. Alzheimer's disease (AD) is a type of ADRD with an insidious onset and a generally progressive deteriorating course for which all other specific causes have been excluded. Other types of ADRD include those related to stroke, mixed dementia (with both Alzheimer's and vascular dementia), and dementias associated with medical conditions such as Parkinson's disease, Huntington's disease, dementia with Lewy Bodies (DLB), AIDS, and alcohol or drug abuse.

This report covers calendar year 2010 (those alive on January 1, 2010), the most recent full year of data available from all reporting sources. Registry cases in this report are defined as Alzheimer's disease (AD), vascular (Vascular), mixed dementias (Mixed) and ADRDs in other medical conditions (Other). Registry cases are identified by location of residence, either in a facility (nursing facilities or residential care facilities), in the community (home or adult day care) or in an unknown location. Exclusions of some demographic information are due to the voluntary method of data collection. It should be noted that many cases may be identified at a late stage of the disease rather than at onset. This affects the time from entry into the Registry until death.

¹ US Census Bureau, Population Division, September, 2013.

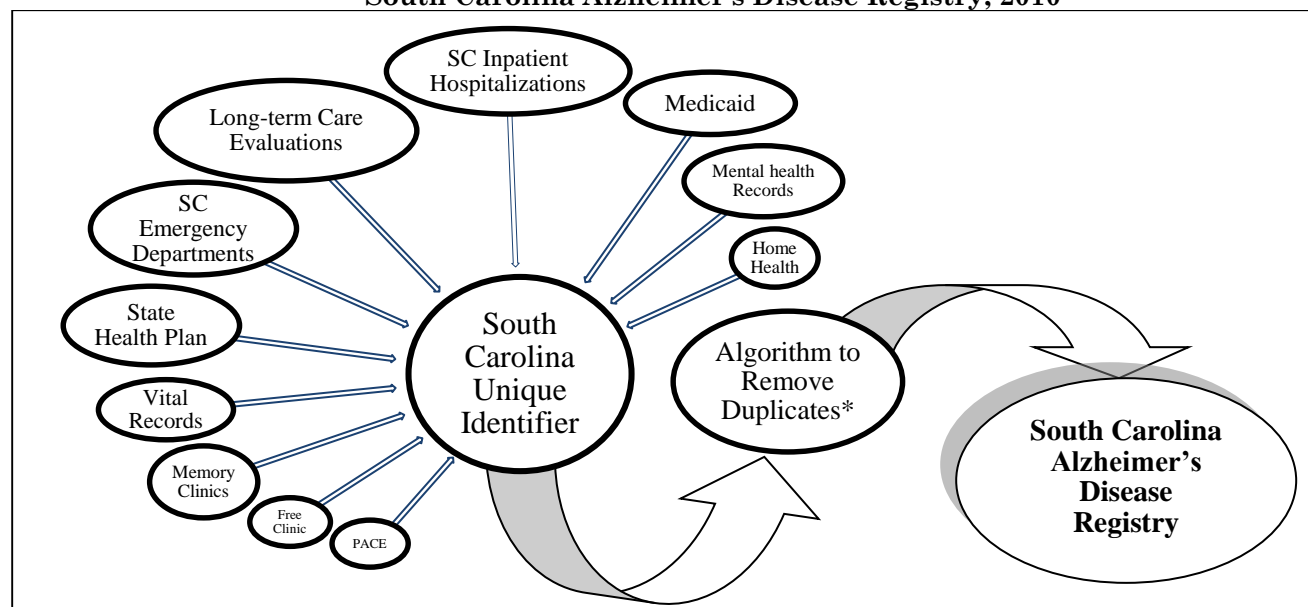
² Alzheimer's Association, 2013 Alzheimer's Disease Facts and Figures.

~ *Alzheimer's Disease and Related Disorders in South Carolina* ~

The prevalence of ADRD in the United States in 1989, was estimated to be over 10 percent among persons aged 65 and older, and about 47 percent among those aged 85 and older.¹ In 1990, 4.3% of South Carolina's total population was 75 years and older; totaling 151,000 residents. By 2000, there were 215,000 South Carolina residents 75 years and older, representing 5.4% of the total population or a 42% increase.²

We do not know the total number of persons with ADRD in South Carolina with certainty. National estimates of ADRD prevalence vary widely from one study to another. Individuals who have mild forms of the disease, but lack a diagnosis, do not appear in our Registry data. Previous studies suggest that the number of individuals with ADRD may be nearly 50% greater than the number with diagnosed ADRD.³ What we do know is that the South Carolina Alzheimer's Disease Registry is the best population-based Registry of ADRD in the country. There are only two other such registries in existence. One, in New York, is in practice limited to records from in-patient hospital stays.⁴ The second is located in West Virginia and began collecting data in May 2008. Our South Carolina Registry uses data from a wide variety of sources to capture as many diagnoses as possible.

Figure 1
Registry Data Sources
South Carolina Alzheimer's Disease Registry, 2010



*Duplicates occur because individuals often use more than one name, social security number, or other identifying information when using health or social services.

¹DA Evans, et al. Prevalence of Alzheimer's Disease in a Community Population of Older Persons; Higher than previously reported. JAMA 1989;262:2551-6.

²US Census Bureau, Population Division, Interim State Population Projections, 2005.

³LE Hebert et al. Alzheimer's Disease in the US Population: Prevalence estimates using the 2000 Census. Archives of Neurology, 2003; Vol. 60, 119-1122.

⁴PP Lillquist. Challenges in Surveillance of Dementias in New York State. Preventing Chronic Disease: Public Health Research, Practice and Policy, 2004; Vol. 1, No. 1, 1-9.

~ History of the Registry ~

1988

The Alzheimer's Disease Registry, previously the Statewide Alzheimer's Disease and Related Disorders Registry, was established in 1988 to record specific information about South Carolinians who develop Alzheimer's disease and related disorders (ADRD).

1990

On May 31, 1990, Governor Carroll A. Campbell, Jr. signed a state law authorizing the Registry. This law (R653, H4924) amended Title 44, Code of Laws of South Carolina 1976, relating to health, by adding Chapter 36 establishing a voluntary Statewide Alzheimer's Disease and Related Disorders Registry in the Arnold School of Public Health, of the University of South Carolina. The law has strict confidentiality requirements but does allow Registry staff to contact the families and physicians of persons diagnosed as having Alzheimer's disease or a related disorder to collect relevant data and to provide information about public and private health care resources available to them.

1993

From July 1993 to May 1996, the Registry was located at the James F. Byrnes Center for Geriatric Medicine, Education, and Research, a geriatric research hospital jointly sponsored by the USC School of Medicine and the SC Department of Mental Health.

1997

The Registry was moved back to the Arnold School of Public Health. The Registry is currently maintained by the Office for the Study of Aging, Arnold School of Public Health, USC.

2009

In 2009 the Alzheimer's Disease Registry celebrated its 20th anniversary. It is one of only three statewide registries for Alzheimer's disease and related disorders in the United States. It continues to collect and provide prevalence data to public and private entities for planning, advocate for caregivers, and foster research in risk factors for ADRD including the risk of institutionalization.

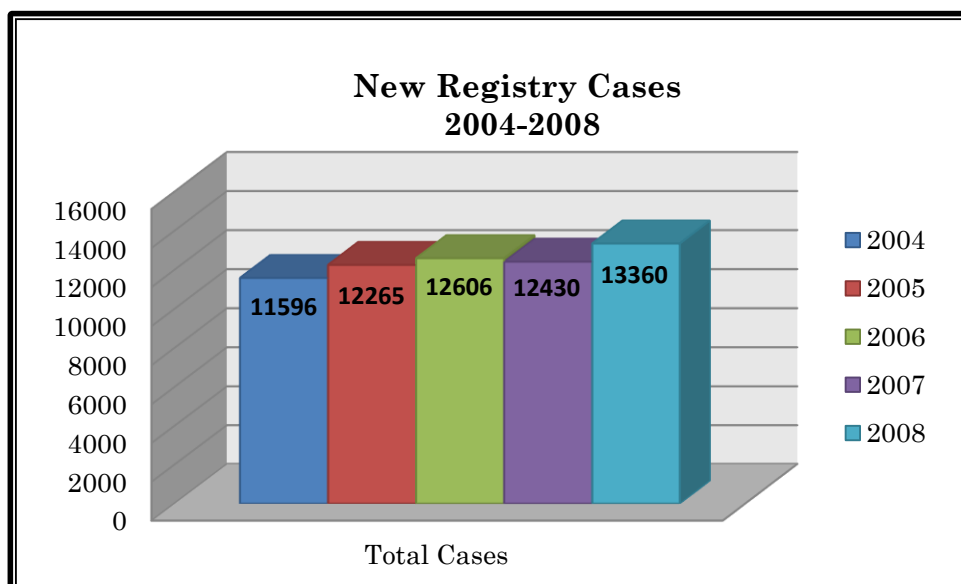
This project has received widespread support and interest from the academic community, lay support groups, state agencies, and other public and private organizations as part of a statewide effort to study the growing impact of Alzheimer's disease on the health and welfare of older South Carolinians.

~ Trends in New Cases of the Alzheimer's Disease Registry in South Carolina from 2004-2008~

There is considerable interest in the possible increase in the number of individuals with ADRD. The SC Alzheimer's Disease Registry is in a unique position to respond to this question with population-based data. This is a report of new cases added to the South Carolina Alzheimer's Disease Registry over the 5 year period from 2004 to 2008. The following are some findings from the data:

- In 2008, a total of 13,360 new cases of ADRD were added to the registry. This total is a 7.5% increase from the previous year and the largest percent change over the 5 year period.*
- The number of new cases added to the registry has increased from 2004-2008 at an average of 2.9% per year. Over the 5 year time period there was one instance where there was a decrease in the number of new cases; this occurred from 2006 to 2007 when the number declined by 1.4%.

Figure 2



* A new data source was added to the registry in 2008, but in order for equivalent comparison to previous years, those cases were not included in the totals for this report on trends in new cases.

Age

From 2004-2008, there has been a steady increase in new cases aged 50 to 84 with the greatest average yearly increase of 10.5% occurring in the 50-64 age group. Upward trends were also seen in the 65-74 and 75-84 age groups. The average yearly increase was 6.8% for the 65-74 age group and 4.0% for the 75-84 age group. The number of new cases in our two extreme age groups, under the age of 50 and 85 and older, has fluctuated over the 5 year time period.

Figure 3
New Registry Cases by Age Group

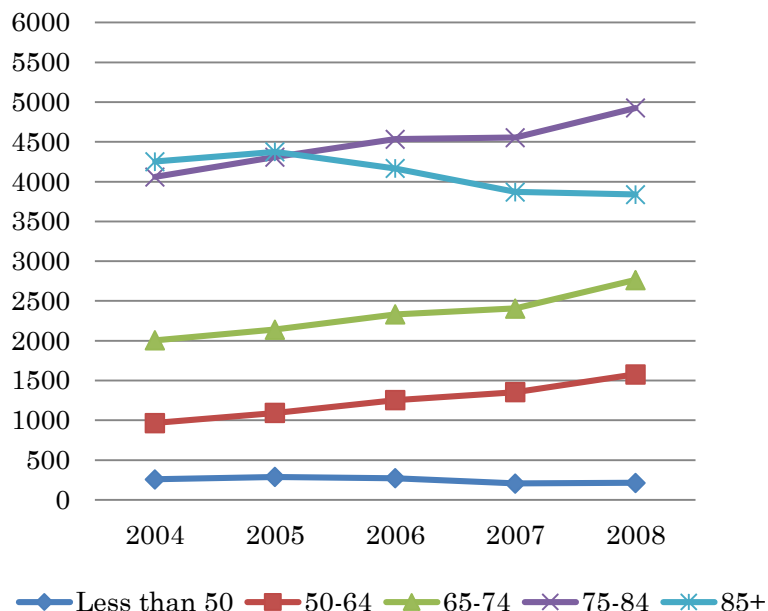
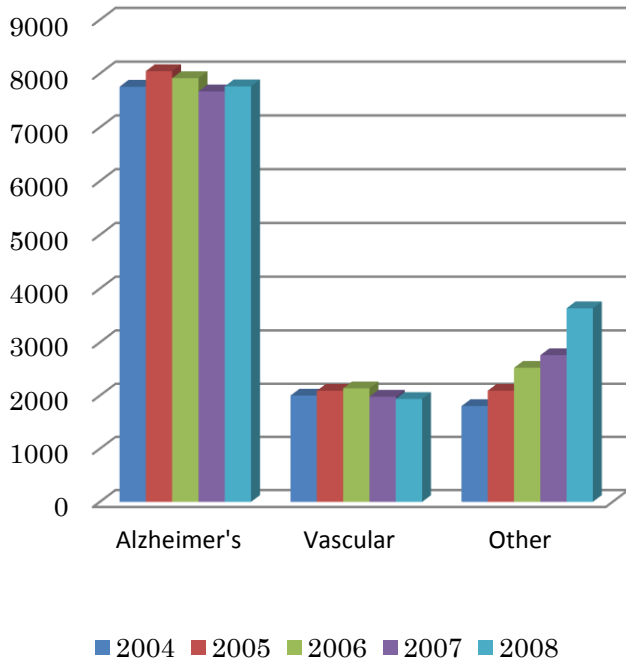


Figure 4
New Registry Cases by Dementia Type



Dementia Type

Over the 5 year time period, the number of new registry cases diagnosed with Alzheimer's disease and vascular dementia remained consistent. There was a marked increase in registry cases diagnosed with "other types" of dementia over the 5 year period with an average increase of 15.6% per year. The "other types" category includes the following diagnoses: Dementia with other conditions, other cerebral degenerations, Alcohol dementia, Parkinson's disease, dementia with Lewy Bodies, HIV/AIDS dementia, drug-induced dementia, Huntington's disease, and organic brain syndrome.

Gender

From 2004-2008, the number of male new cases has increased an average of 3.5% per year while the number of female new cases increased an average of 2.7% per year. As expected, the total number of new cases has been higher among females than males over the 5 year time period, although the average yearly percent increase for males has been greater than the average yearly percent increase for females.

Race

The total number of new cases has been higher among Whites than African Americans from 2004-2008. The number of Whites has increased an average of 3.1% per year. The number of African American new cases fluctuated from year to year and did not have the clear upward trend as seen in the White new cases. The number of Hispanics stayed consistent over the 5 year time period.

Conclusion

The Alzheimer's Disease Registry is capturing more and more new cases of ADRD in South Carolina every year. Some noteworthy findings from this trend analysis are:

- The greatest average yearly increase of 10.5% occurred in the age group of 50-64. These results suggest that, over the 5 year time period, the number of individuals diagnosed with ADRD has been the highest in what is considered a "younger" age group in the ADRD spectrum. This has important implications since the Baby Boomers will not have arrived at the age of 65 until 2011, and this report is based on data through 2008.
- There is an average yearly increase of 15.6% in new Registry cases diagnosed with "Other types" of dementia. These findings suggest that, over this 5 year time period, there may have been improvements in ADRD diagnosis allowing for more specific conclusions related to disease type.

****NOTE:** Since the creation of this report, new data sources have been added to the registry. The trends report will be updated in next year's annual report highlighting trends in new cases for the years 2008-2011.

~CHARACTERISTICS OF ADRD IN SOUTH CAROLINA~

BASED ON 2010 ALZHEIMER'S DISEASE REGISTRY DATA

Since January 1, 1988, 199,279 cases of Alzheimer's disease and related disorders (ADRD) have been identified in South Carolina. This report describes demographic characteristics and medical information for the 82,772 cases alive on January 1, 2010, displayed by type of ADRD.

Type of ADRD

Among the 82,772 current Registry cases, 62 percent had a diagnosis of Alzheimer's disease and 11 percent had a diagnosis of vascular dementia, which is often associated with stroke. In the event of records showing both Alzheimer's disease and vascular dementia the case was reported in a Mixed dementia category. Four percent of all Registry cases are in the Mixed category. The additional 24%, for the total number of "Other Conditions," had a dementia related to other medical conditions, such as Parkinson's disease (see Table 2 for complete listing). The diagnosis shown represents the most current diagnosis in the data received.

Location

More registry cases resided in the community (65%) than in a nursing facility (30%) or unknown locations (5%) (Figure 5). As shown in Figure 6, the distribution of the types of ADRD was similar in the community and in nursing facilities.

Table 1
Registry Cases by Dementia Type
and Community, Nursing Facility or Unknown Location
 South Carolina Alzheimer's Disease Registry, 2010

Dementia Type	Community		Nursing Facility		Unknown		Total	
	N	%	N	%	N	%	N	%
Alzheimer's disease	32,827	61	15,943	64	2,191	52	50,961	62
Vascular dementia	5,668	11	2,839	11	274	7	8,781	11
Mixed dementia	2,157	4	1,254	5	88	2	3,499	4
Other conditions	12,910	24	4,956	20	1,665	40	19,231	24
Total	53,562	65	24,992	30	4,218	5	82,772	100

~ *Location and ADRD in South Carolina* ~
(continued)

Figure 5
Registry Cases by Community,
Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2010

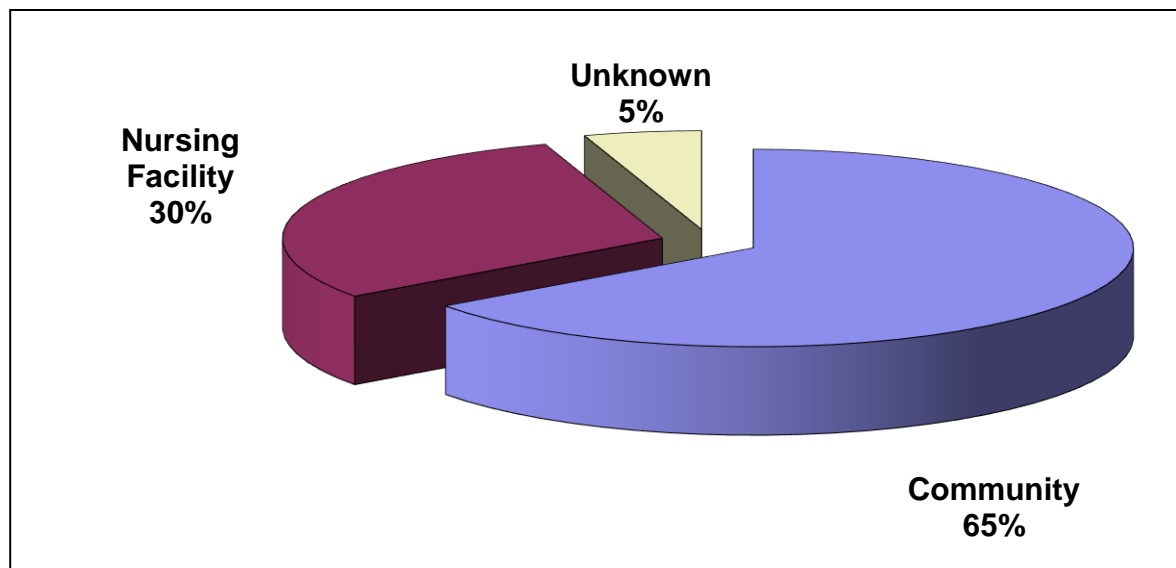
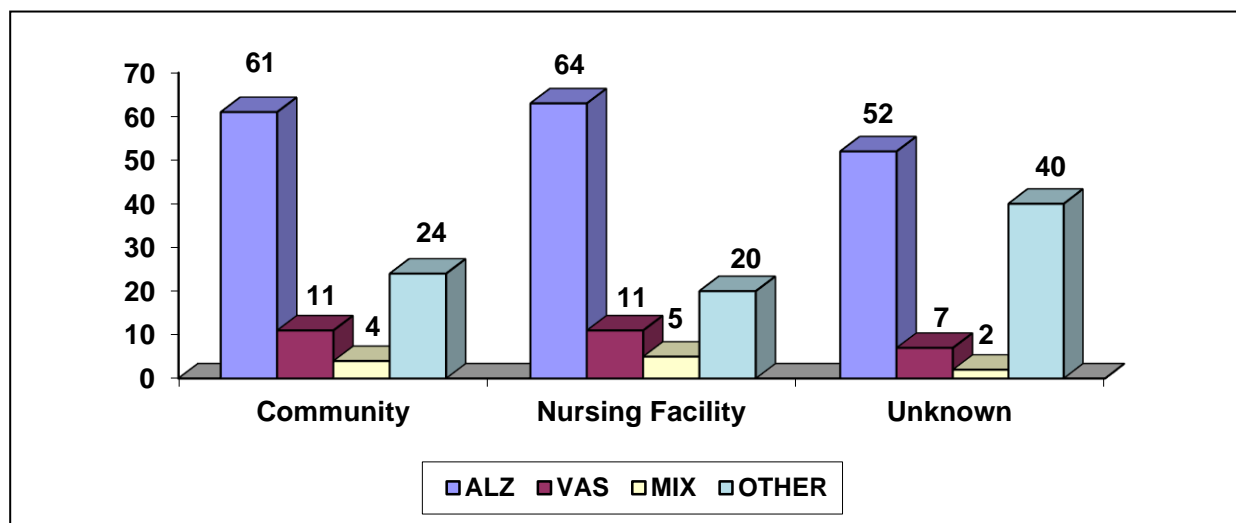


Figure 6
Registry Cases in Community,
Nursing Facility or Unknown Location,
by Dementia Type
South Carolina Alzheimer's Disease Registry, 2010



~ *Dementia in Other Medical Conditions* ~

In addition to Alzheimer's disease, the Registry tracks dementias that are associated with other medical conditions, such as Parkinson's disease, alcohol and drug abuse, and HIV/AIDS. In the 2010 Registry, there are 19,531 persons with a dementia associated with one of these conditions, who do not also have a diagnosis of Alzheimer's disease or vascular dementia. Six percent have dementia associated with Parkinson's disease, and 30% have an indication of dementia associated with some other medical condition (please see Table 2 footnote). The percentages in the table are not mutually exclusive due to the fact that some persons' records indicate that they have more than one medical condition. A few individuals have as many as three such conditions.

Dementia with Lewy Bodies

Dementia with Lewy Bodies (DLB) is a progressive brain disease characterized by abnormal round structures in the areas of the brain that control thinking and movement. Hence, DLB causes symptoms similar to those commonly associated with both Alzheimer's disease and Parkinson's disease. Like Alzheimer's disease, it can cause confusion, memory loss, and depression, while other possible symptoms are slowed movement, rigid muscles, and tremors, these symptoms normally found in those with Parkinson's disease. Persons with DLB may also have hallucinations and experience day-to-day changes in their symptoms. Currently, there is no cure for Dementia with Lewy Bodies. Medications used to treat Alzheimer's disease, Parkinson's disease, and depression are typically used to manage DLB symptoms. Dementia with Lewy Bodies (DLB) is the second most common cause of dementia, after Alzheimer's disease. Estimates suggest that DLB accounts for approximately 20% of all dementia cases.¹

Table 2
Dementia in Other Medical Conditions by Age Group
South Carolina Alzheimer's Disease Registry, 2010*

	Under 65	65–74	75–84	85+	Total	
	%	%	%	%	N	%
Alcohol dementia	18	7	2	1	1438	6
Drug-induced dementia	1	0	0	0	80	0
Organic brain syndrome	0	0	0	0	17	0
Other cerebral degenerations	41	59	53	39	10739	44
Parkinson's disease	2	5	8	7	1255	6
Huntington's disease	0	0	0	0	26	0
HIV/AIDS dementia	5	0	0	0	248	1
Dementia with Lewy Bodies	2	7	10	7	1573	7
Frontotemporal dementia	1	0	0	0	64	0
Pick's disease	0	0	0	0	44	0
Creutzfeldt-Jakob disease	0	0	0	0	2	0
Chronic Traumatic Encephalopathy	0	0	0	0	4	0
Dementia with other conditions*	30	20	25	46	6726	30
Total (N)	4727	5077	6714	5698	22216	

*Dementia with other conditions includes those with an ICD-9-CM code in 294.1(dementia in conditions classified elsewhere) on their medical record. This code is listed along with the ICD-9-CM code of the dementia-causing condition. However, the dementia-causing condition may not be identifiable from the record, and therefore, may not be in the above table.

¹ Lewy Body Dementia Association. www.lewybodydementia.org. Accessed March 7, 2008

Chronic Traumatic Encephalopathy (CTE): An Emerging Dementia Among Professional Athletes and Others

Chronic traumatic encephalopathy, commonly known as CTE, is a progressive neurodegenerative disease caused by repetitive head trauma. Persons with CTE suffer a progressive decline of memory and cognition. They may also experience depression, suicidal behavior, poor impulse control, aggressiveness, parkinsonism, and eventually, dementia.

Dr. Harrison Martland first described CTE in his 1928 article “Punch Drunk”, published in the *Journal of the American Medical Association*, after observing a number of symptoms among boxers.¹ Since then, CTE has gained more prominence being associated with several sports, including football, wrestling, hockey, and soccer, as well as with other circumstances where repetitive mild head trauma is likely, such as epileptic seizures, physical abuse, and among military veterans.

Similar to Alzheimer’s disease, the onset of CTE is often gradual and does not progress rapidly. Persons suffering from CTE may often be diagnosed with Alzheimer’s disease or frontotemporal dementia, depending on the age of onset and symptoms. In older individuals experiencing memory problems, a diagnosis of Alzheimer’s disease may be made when in fact the individual

“CTE... the only known neurodegenerative dementia with a specific identifiable cause... head trauma.”

may have both Alzheimer’s and CTE. In younger individuals (ages 40-50) exhibiting behavioral issues, a diagnosis of frontotemporal dementia may be made instead of CTE.²

In the summer of 2013, the NFL reached a tentative \$765 million settlement over concussion-related brain injuries among its 18,000 retired players. The settlement included an agreement to compensate victims, pay for medical exams, and facilitate research. More than 4,500 former NFL players sued the league, but all former NFL players would be eligible. Under the settlement, individual awards would be limited to \$5 million for players with Alzheimer's disease; \$4 million for those diagnosed after their deaths with chronic traumatic encephalopathy; and \$3 million for players with dementia.³

Research into CTE is still evolving. So far, little is known about the number of head injuries or severity necessary to lead to CTE later in life. Currently, the only way to definitively diagnosis CTE is by examining brain tissue after death. However, researchers are working to discover biological indications of the disease to detect CTE prior to death, to monitor its progression, and to develop effective treatments to prevent, delay, or potentially reverse the condition.²

The SC Alzheimer’s Disease Registry has begun surveillance of the occurrence of CTE among South Carolinians. Future research into statewide prevalence, demographics, and related conditions is planned.

1 Martland, HS. Punch Drunk. *Journal of American Medical Association* 1928; 91: 1103-1107.

2 Gavett, BE, Stern RA, McKee AC. Chronic traumatic encephalopathy: a potential late effect of sports-related concussive and subconcussive head trauma. *Clin Sports Med* 2011, 30(1): 179-xi.

3 Associated Press. “NFL, ex-players agree to \$765M settlement in concussions suit.” August 29, 2013.

<http://www.nfl.com/news/story/0ap1000000235494/article/nfl-explayers-agree-to-765m-settlement-in-concussions-suit>

~ Age and ADRD in South Carolina ~

Table 3 shows that 42% of persons with Alzheimer's disease are 85 years of age or older. Figure 7 shows this information graphically for all dementias included in ADRD, with 37% of persons over 85 years of age. Figure 8 indicates that for people with ADRD, over 65% of those 75 to 84 years of age are being cared for in the community. Living in the community is most often the location of choice for the individual and family. However, as Figure 8 indicates, with age comes an increase in movement to nursing facilities.

Table 3
Registry Cases by Age Group and Dementia Type
South Carolina Alzheimer's Disease Registry, 2010*

	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
AGE										
Under 65	3,076	6	1,206	14	186	5	3,490	19	7,958	10
65 – 74	8,492	17	1,950	24	674	19	4,447	24	15,563	19
75 – 84	17,199	35	2,805	33	1,274	37	5,580	30	26,858	34
85 +	20,821	42	2,582	30	1,333	38	5,069	27	29,805	37
Total	49,588	62	8,543	11	3,467	4	18,586	23	80,184	100

*2,588 records for individuals have missing values for the variables required for inclusion in this table or have ages either less than 50 or greater than 110.

AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 7
Registry Cases by Age Group
South Carolina Alzheimer's Disease Registry, 2010

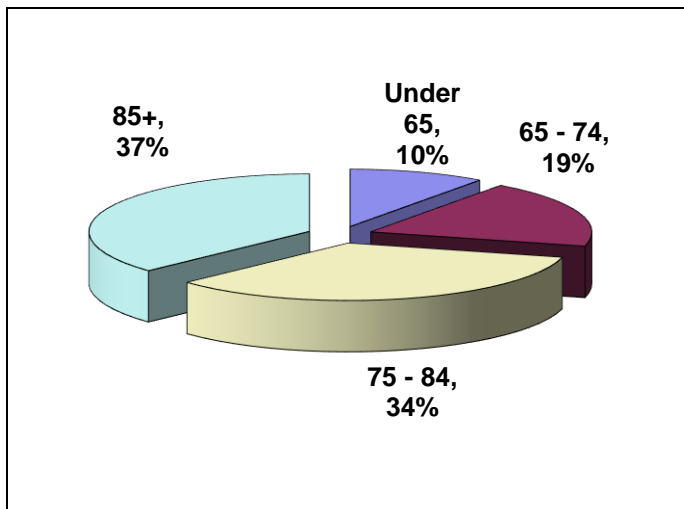
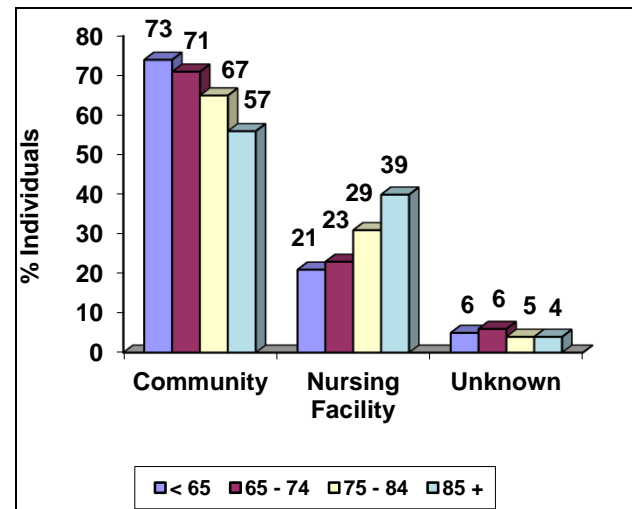


Figure 8
Registry Cases by Age Group in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2010



~ Gender and ADRD in South Carolina ~

Table 4 shows Registry cases by gender, dementia type, and age group. For each dementia type, the number of women is notably larger than the number of men in all but the youngest age category. In particular, among those age 85 or over, the number of women with ADRD is over 3 times the number of men with ADRD. More women than men in this population were diagnosed with ADRD (Figure 9). This is likely due to the larger number of women alive after age 75. The differences in the ADRD diagnoses by gender are shown graphically in Figure 10.

Table 4
Registry Cases by Gender, Age Group and ADRD Type
South Carolina Alzheimer's Disease Registry, 2010*

	<i>AD</i>		<i>VASCULAR</i>		<i>MIXED</i>		<i>OTHER</i>		<i>TOTAL</i>	
	N	%	N	%	N	%	N	%	N	%
MEN										
Under 65	1,409	9	658	19	104	8	2,042	26	4,213	15
65 – 74	3,470	22	940	27	326	26	2,195	28	6,931	25
75 – 84	5,683	37	1,131	33	482	38	2,159	28	9,455	34
85 +	4,973	32	720	21	352	28	1,383	18	7,428	27
WOMEN										
Under 65	1,661	5	547	11	82	4	1,438	13	3,728	7
65 – 74	5,015	15	1003	20	348	16	2,241	21	8,607	17
75 – 84	11,491	34	1,671	33	790	36	3,391	32	17,343	33
85 +	15,789	47	1,854	37	975	44	3,627	34	22,245	43

*2,588 records for individuals have missing values for gender or have ages either less than 50 or greater than 110.

AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 9
Registry Cases by Gender

South Carolina Alzheimer's Disease Registry, 2010

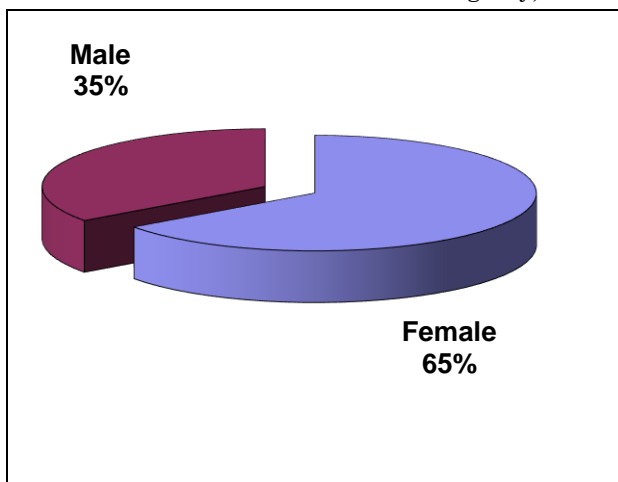
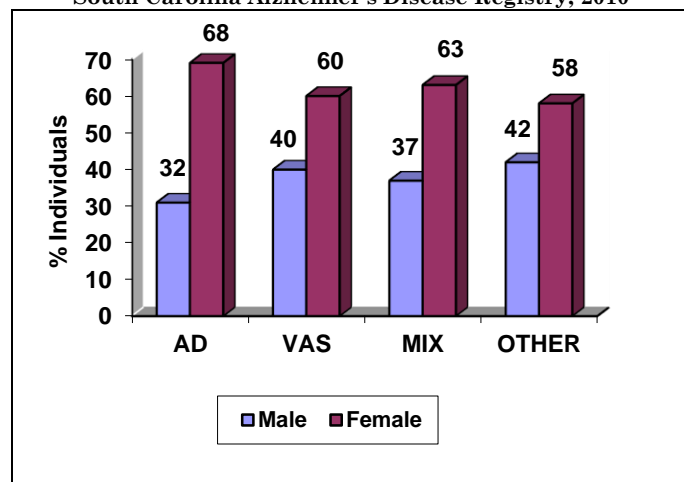


Figure 10
Registry Cases by Gender and ADRD Type

South Carolina Alzheimer's Disease Registry, 2010



~ Race and ADRD in South Carolina ~

Compared with Whites, African Americans, who comprise approximately 20% of the South Carolina population 65 years and older, were over-represented in vascular dementia (38%) and in the overall Alzheimer's Disease Registry (29%)(Table 5). Sixty-five percent of African Americans with ADRD reside in the community, compared to 62% of Whites living in the community (Figure 12).

Table 5
Registry Cases by Race and ADRD Type

South Carolina Alzheimer's Disease Registry, 2010*

	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
RACE										
White	33,268	65	4,846	55	2,084	60	11,958	61	52,156	63
African-American	13,267	26	3,367	38	1,091	31	6,271	32	23,996	29
Hispanic	199	<1	40	1	4	<1	93	1	336	<1
All Others	4,227	8	528	6	320	9	1209	6	6,284	8
Total	50,961	62	8,781	11	3,499	4	19,531	24	82,772	

*AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Figure 11
Registry Cases by Race

South Carolina Alzheimer's Disease Registry, 2010

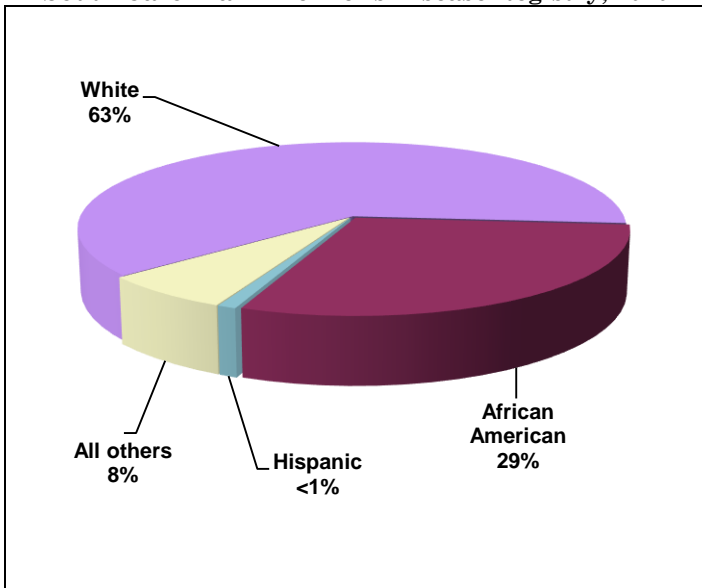
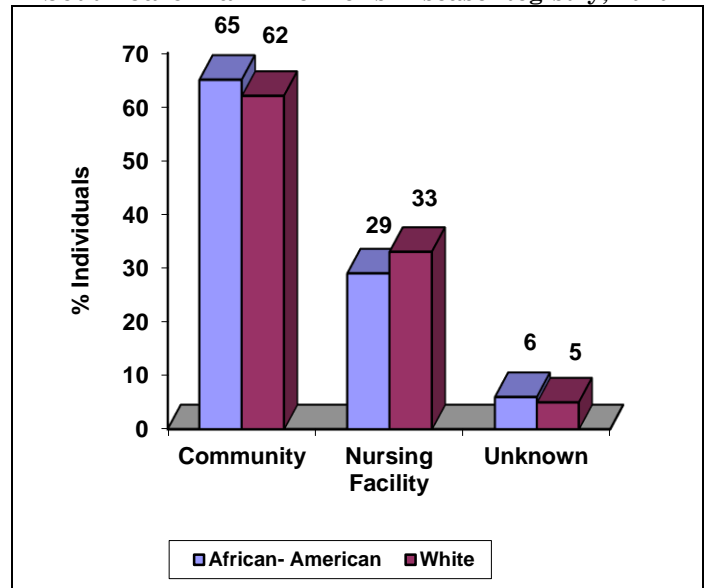


Figure 12

Registry Cases by Race in Community, Nursing Facility or Unknown Location
South Carolina Alzheimer's Disease Registry, 2010



~ Deaths among Individuals in the Registry ~

The Alzheimer's Disease Registry data are linked with death certificates to summarize the deaths occurring among persons in the Registry. Of those people identified with ADRD since 1988, 124,726 have died. The individual's first date of diagnosis may not be known to the Registry in every instance. For example, if an individual is first diagnosed during a physician office visit, then that diagnosis is not available to the Registry. We use the first date that a person entered one of the systems reporting to us as their entry date (Table 6).

Table 6
Length of Time from Entry to Death by ADRD Type
South Carolina Alzheimer's Disease Registry, 2010*

ENTRYto DEATH	AD		VASCULAR		MIXED		OTHER		TOTAL	
	N	%	N	%	N	%	N	%	N	%
< 2 years	47,785	59	9,686	63	4,081	56	13,492	69	75,044	60
2–5 years	21,942	27	3,669	24	2,224	31	4,321	21	32,156	26
5 + years	11,947	15	2,020	13	1,019	14	2,540	13	17,526	14
Total	81,674	66	15,375	12	7,324	6	20,353	16	124,726	100

AD=Alzheimer's disease or senile dementia; VASCULAR=Vascular dementia; MIXED=both Alzheimer's disease and Vascular dementia; OTHER=dementia in other medical conditions.

Table 7 lists the top 10 underlying causes of death for persons 65 years of age or older in the South Carolina Alzheimer's Disease Registry who died during 2010. The #1 underlying cause of death for these persons was attributed to senility and organic mental disorders. This category includes Alzheimer's disease and many other dementing illnesses. Nationally, the leading causes of death for persons ages 65 years and older were: heart disease, cancer, chronic lower respiratory diseases, cerebrovascular disease, Alzheimer's disease, diabetes, influenza and pneumonia, nephritis, accidents, and septicemia.¹ As can be seen in the table below, the underlying causes of death for those with ADRD in the Registry nearly mirror the national trend.

Table 7
Top 10 Underlying Causes of Death Among Those 65 Years or Older
South Carolina Alzheimer's Disease Registry, 2010*

Rank	
1	Senility and organic mental disorders
2	Acute cerebrovascular disease
3	Coronary atherosclerosis and other heart disease
4	Chronic obstructive pulmonary disease and bronchiectasis
5	Acute myocardial infarction
6	Parkinson's disease
7	Congestive heart failure; nonhypertensive
8	Pneumonia**
9	Cancer of bronchus; lung
10	Diabetes mellitus without complication

*Only includes persons who died during the 2010 calendar year.

**Excludes pneumonia caused by tuberculosis or sexually transmitted disease.

1 CDC/NCHS, National Vital Statistics System. Xu JQ, Kochanek KD, Murphy SL, Tejada-Vera B. Deaths: Final data for 2009. National vital statistics reports; vol 61 no 7. Hyattsville, MD: NCHS; 2012.

~ Registry Procedures ~

A definitive diagnosis of ADRD is difficult, especially in the early stages. The registry staff is not directly involved in diagnosis; the physician's diagnosis is collected from the individual's medical records through codes using the International Classification of Diseases, 9th revision, Clinical Modification (ICD-9-CM, 2010). An individual is then classified into four general categories for reporting purposes as shown in Table 8.

Individuals with ADRD are usually identified, as they (or their family members) seek provider services. Since no single system identifies all newly diagnosed patients with ADRD, cases are collected from several sources (see Figure 1, page 5).

Table 8
Classification of ADRD by ICD-9-CM Codes
 South Carolina Alzheimer's Disease Registry, 2010

ALZHEIMER'S DISEASE	
290.0 - 290.3	Senile or presenile dementia
290.8 - 290.9	
331.0	Alzheimer's disease
VASCULAR DEMENTIA	
290.4 - 290.43	Arteriosclerotic dementia
435 - 438	Cerebrovascular disease (with a dementia code*)
MIXED DEMENTIA	
Both Alzheimer's disease and Vascular dementia	
DEMENTIA IN OTHER MEDICAL CONDITIONS (see note below)	
291.2	Alcohol dementia
292.82	Drug-induced dementia
294.1	Dementia with other conditions
331.82	Dementia with Lewy bodies
331.11	Pick's disease
331.19	Frontotemporal dementia
The following conditions are included with a dementia code*:	
046.1	Creutzfeldt-Jakob disease
310.1	Organic brain syndrome
310.2	Chronic traumatic encephalopathy
331.1 - 331.9	Other cerebral degeneration
332.0 - 332.1	Parkinson's disease
333.4	Huntington's disease
042	HIV

NOTE: In the case where a person's record contains multiple indicators of the above categories, Alzheimer's disease and vascular dementia take precedence, except in the case where there are indications of both Alzheimer's disease and vascular dementia. In this case, the person is classified as having mixed dementia. Those classified with dementia in other medical conditions have no indications of Alzheimer's disease or vascular dementia.

*One of the following dementia codes must also be present: 290.0-290.3, 290.8-290.9, 331.0, 290.4-290.43, 291.2, 292.82, 294.10, 294.11, 331.82.

~ *Registry Core Data Items* ~

The registry core data set (Table 9) consists of case-identifying data and diagnostic data (ICD-9-CM codes), and the place from which the records were obtained. Other information collected, *if available*, includes other medical diagnoses, educational status, caregiver contact data for follow-up and marital status.

Table 9
Registry Core Data Items
South Carolina Alzheimer's Disease Registry, 2010

Identification of case (for matching purposes only)
Location of case (for follow-up)
Name and location of caregiver/contact person (*if available*)
Sociodemographic data (education, marital status, gender, race, age)
Diagnosis (current dementia diagnosis and other medical diagnoses)

~Research Projects & Other Activities~

In addition to registering and tracking individuals with ADRD, the staff of the Alzheimer's Disease Registry and Office for the Study of Aging (OSA) also conduct other activities focused on aging issues of older individuals.

Research

Association between Behavioral Disturbances and Nursing Home Admission in Patients with Alzheimer's disease

The Office for the Study of Aging was provided funding in September 2010 to conduct phone interviews with caregivers of individuals with Alzheimer's disease to determine risk factors for the decision to place the individuals in institutions (cases) rather than keeping them at home (controls). The drug company that provided funding was particularly interested in validating a particular tool called the Neuropsychiatric Inventory (NPI). It asked questions about 12 different sets of problem behaviors and the frequency, severity and bothersomeness of the behavior to the caregiver. Those behaviors were delusions, hallucinations, agitation/aggression, depression, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability, aberrant motor behavior, sleep and nighttime behavior disorders, and appetite and eating changes. We also asked questions from the Zarit Burden Interview and the CES-D depression scale and captured information on the caregivers' feelings of role captivity, competency, and demographics.

We completed 705 interviews, including 363 cases (individuals with Alzheimer's disease in nursing homes) and 342 controls (individuals with Alzheimer's disease cared for at home). These individuals were identified, using the Alzheimer's Disease Registry, with Alzheimer's disease by self report and the diagnosis confirmed by ICD-9 code found on a hospital discharge or emergency room visit files.

By using a propensity score matching system to match on race, gender, age within 5 years and assessment for nursing home placement eligibility within 120 days of study initiation, 354 cases matched with 289 controls. The race of the caregivers and the clients were almost the same with 163 controls and caregivers of the controls being African American and 156 cases and 157 caregivers of cases being African American. 126 controls and caregivers of controls were Caucasian and 196 cases and caregivers of cases (195) were Caucasian. More than 75% of the caregivers were females (253 cases; 211 controls) and 80% of the caregivers for cases reported being a high school graduate or higher education while 72% of the control caregivers reported being a high school graduate.

The analysis showed that the NPI Total Score was found to be a statistically significant predictor of Nursing Home Admission (NHA), where each 10% increase in score (i.e., more impairment) resulted in 30% greater odds of NHA; the NPI-4 Score (consisting of the combined scores from the following behaviors: agitation/aggression, irritability, disinhibition, and aberrant motor behavior) resulted in a 21% greater odds of NHA.

~*Research Projects & Other Activities (continued)*~

Nursing home admissions were more likely to occur if the caregivers were males or married. NHA was also more likely if the person with AD had more psychiatric conditions or had an increased risk for morbidity based on the Charleson Comorbidity Index (a widely used index of comorbid conditions derived from the assessment for nursing home placement).

We also asked the open-ended question “What was the main reason for placing your ____ (relationship) in the nursing home? (cases) or What is the main reason for keeping your ____ (relationship) at home? (controls).

The qualitative analysis of the open-ended questions showed that overall, in our control group, the most frequently reported theme was *issues with caregivers* which contained themes involving a sense of obligation (n=161), emotions (n=20), help (n=25), and opportunity (n=27). The results of our qualitative analysis suggest that caregivers’ issues play a major role in the decision to keep ones loved one at home rather than placing them in a nursing home.

Among the cases, the most frequently reported theme was *issues with the patient* which contained themes involving physical health problems (n=219), behavior problems (n=121), hospice (n=7), loss of ability to self care (n=56), and medication problems (n=12). The results of our qualitative analysis suggest that patient issues play a major role in the decision to place a loved one in a nursing home rather than at home.

Although our work with the drug company is complete, a manuscript “Evaluating the association between behaviors and nursing home placement for persons with Alzheimer’s: Combining prospective and retrospective data sources“ is under review. Further analysis is in progress in preparation for a manuscript focusing on racial difference that may drive decisions by caregivers to place their loved ones in a nursing home or care for them at home.

Faith and Health

The USC Faith and Health Project explored the complex patterns related to social capital, aspects of faith, and health through in-depth interviews and brief survey instruments. Study groups included United Methodist members who had participated in a holistic health program, regular attendees of United Methodist churches (not part of the holistic health program) and infrequent /non-attendees of religious services, with each category stratified by race (AA and Caucasian). Based on findings and existing literature, a survey instrument has been developed to assess social capital, health outcomes, and multiple dimensions of faith and practice. Two manuscripts from this project are currently under review.

Exercise

Move for Life

OSA in collaboration with a Duke Endowment Grant and other Arnold School of Public Health Departments has developed an exercise DVD designed to increase physical activity. These exercises are for adults who are 50 years and older and younger people who have not been exercising regularly or who have limitations. The DVD contains exercise instructions, deep breathing and stretching, strength and balance exercises and a cardio routine in 10 minute segments or a full routine of 28 minutes. Further information can be found at www.sph.sc.edu/osa.

Placemat Strength Training Program

Training home care workers to assist clients in maintaining independence by improving physical functioning through strength training has resulted in the Placemat Strength Training Program (PSTP). This exercise program has been specifically designed for the person who has met nursing home level of care and has chosen to remain at home. This program is being implemented through Community Long-Term Care and is also available to the public at large. See www.sph.sc.edu/OSA/programs_placemat.html.

Training

Dementia Dialogues

“**Dementia Dialogues**” consists of 5 parts, each approximately 1.5 hours in length. Part 1 consisted of “**The Basic Facts**”, an overview of ADRD, Part 2 “**Keeping the Dialogue Going**”, strategies for effective communication, Part 3 “**It’s a Different World**”, understanding the impact of the environment and ways to promote independence in activities of daily living, Part 4 “**It’s Nothing Personal**”, addresses challenging behaviors and Part 5 “**Now What Do I Do**”, creative problem solving.

Each participant receives a certificate of participation for each unit and a Dementia Specialist Certificate upon completing all five units. The program is offered at no cost to participants and is held regionally by certified trainers. Training materials are also available on the Office for the Study of Aging website. ***Over 20,000 professional, non- professional and family caregivers in South Carolina have received this training.*** For further information including training materials and contact information for trainers please visit www.sph.sc.edu/OSA/programs_dementia.html.

~Research Projects & Other Activities (continued)~

Elder Mistreatment Prevention Training

The OSA, in collaboration with the Center for Child and Family Studies in the College of Social Work and with the support of the SC Department of Health and Human Services has developed an Elder Mistreatment Prevention Training called ***We Each Have a Story*** which is available for nursing home management and direct care staff. For further information including training materials and contact information for trainers please visit http://www.sph.sc.edu/OSA/programs_elder.html.

Recruitment and Retention Training

Partnerships around CNA Training and Mentoring (PACT) Program

OSA staff in collaboration with Goodwill Industries of Upstate/Midlands South Carolina, Inc. completed a pilot program that trains and supports nurse aides to become certified, employed and retained. This project is in response to:

- the increased need for trained direct care workers in long term care facilities
- employers' desire for experienced workers
- the need for new CNAs to acquire enhanced training beyond the basic CNA training
- the turnover of direct care workers

OSA was involved in training mentors in the placement facilities as well as providing enhanced monthly training to the newly placed CNAs and facility mentors by providing monthly "Lunch & Learn" sessions on Chronic Disease Management for one year at participating facilities.

The CNAs involved in the PACT program increased their knowledge of Chronic Disease through the modules presented at the Lunch & Learn Sessions. Mentoring increased CNA job satisfaction and retention.

Recruitment and Retention Training and Technical Assistance

Practical solutions and tools are included in a series of courses on issues surrounding recruitment and retention of direct care staff in long term care. This training and technical assistance is available to assist administrators and managers to maintain a quality staff to provide services to the aging and disabled population. For course descriptions: http://www.sph.sc.edu/osa/programs_recruitment.html.

Technical Assistance & Evaluation

Person-Centered Hospital Discharge Planning Model

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. The person-centered approach allows consumer-direction to take place. In collaboration with the SC Lt. Governor's Office on Aging, OSA staff was involved in a Center for Medicare and Medicaid services grant to identify and evaluate a person-centered hospital discharge planning model. Activities include being members of the core planning team, providing training and technical assistance in person-centered planning, and outcome evaluation.

Caregiver Coaching Service

The Office for the Study of Aging staff is working in collaboration with the South Carolina Department of Health and Human Service Community Long Term Care (CLTC) staff to pilot a Caregiver Coaching Service (CCS) to provide training to family caregivers of CLTC participants in order to improve the caregivers' competence in specific areas. Topics include Dementia care, Incontinence care, and a Wellness module to promote resilience and empowerment of the caregivers.

Thirty caregivers received this service; fifteen caregivers completed both the pre and post survey. Although a small sample size prohibits the ability to make true statistical inferences, the descriptive data from the pre and post surveys provide some preliminary information about the effectiveness of the CCS; caregiver burden, depression and perceived stress were reduced. There was an increase in reporting of the positive aspects of caregiving.

Each unit of the CCS was documented by the Caregiver Coach in the CCS Summary Report. Analysis of the reports shows that employing the collaborative coaching approach engages, educates and empowers caregivers to identify and take action to address their concerns. The 30 caregivers identified specific concerns of varying natures. Even when similar concerns were identified, caregivers addressed them differently based on their values, resources, and support.

South Carolina Vulnerable Adult Volunteer Guardian ad Litem Program (SCVAGAL)

In 2012 in South Carolina, there were over 3,000 reported cases of abuse, neglect, or exploitation of vulnerable adults. Over 500 of these reports resulted in legal action. The Office for the Study of Aging, in collaboration with the Department of Health and Human Services, Department of Social Services, Adult Protective Service, Adult Protection Coordinating Council, the South Carolina Bar, and the South Carolina Legal Services and Court Administration, has developed and is continuing a pilot program that will recruit, train and support volunteer Guardians ad Litem to act in the best interest for vulnerable adults under Adult Protective Services custody in cases of abuse, neglect and exploitation.

The statewide program became operational August 1, 2011. Twenty-three (23) volunteers have received training developed by the Office for the Study of Aging. After completing the training, the volunteers are responsible for gathering information, interviewing the vulnerable adult and other involved parties, and making recommendations to the court as to what is in the best interest of the vulnerable adult. The volunteers will be court appointed and will appear in court on behalf of the vulnerable adult. Since August 1, 2011, 220 vulnerable adults have been served in twenty counties. Most cases are self neglect and of these, a large percentage have a diagnosis of dementia.

This pilot program is being evaluated to identify the volume of cases, the number of volunteers needed, the time commitment involved and the associated costs. Persons interested in additional information or in becoming a volunteer Guardian ad Litem can contact SCVAGAL at (803) 629-0277 or by email at SCVAGAL@mailbox.sc.edu.

~Research Projects & Other Activities (continued)~

Program Development

HOME CARE +

On July 1, 2012 the Office for the Study of Aging received a Centers for Medicare and Medicaid Services Innovation Challenge Award. In partnership with select Personal Care Provider Agencies across South Carolina, a unique care coordination model is being implemented targeting dual eligible, frail elderly individuals who desire to remain in their homes. The program will address three main issues: 1) **Better Care** by utilizing person-centeredness and health care coaching, 2) **Better Health** through chronic disease management and medication adherence education and a team approach 3) **Lower Cost** through these improvements. The project will train personal care aides to serve as “Home Care Specialists,” working on teams with “Home Care Consultants” to provide chronic disease management and health care coaching. The “Home Care Consultant” will provide education, support and care coordination to the individual and his/her family on a long-term basis. This approach hopes to reduce avoidable hospitalizations and emergency room visits and delay referral to nursing homes. Currently there are eight sites across the state that have implemented HOME CARE + with 167 beneficiaries enrolled and being served.

Community Outreach

The staff of the Office for the Study of Aging provides expertise and technical assistance to the community through its involvement on committees includes: Alzheimer’s Resource Coordination Center, Advisory Committee for Nurse Aide Training, Nurse Aide Training Coordinators & Instructors Annual Workshop, and the South Carolina Respite Coalition.

The Purple Ribbon Task Force was created by a concurrent resolution adopted by the General Assembly to study the current and future impact of Alzheimer’s disease in South Carolina and assess the resources for the needs of persons with Alzheimer’s disease and related disorders so as to develop a state strategy to address this health issue. An OSA staff member was appointed to this task force and participated in the development of recommendations. A final report entitled “Conquering the Specter of Alzheimer’s Disease in South Carolina” was submitted to the General Assembly. The report can be found at <http://aging.sc.gov>.

~ *Registry Staff* ~

Carol B. Cornman, R.N., P.A., Director of the Alzheimer's Disease Registry and related projects. She handles all requests for information from the Registry. Her research interests include ethnic differences in ADRD, incorporating wellness activities that maintain independence in the elderly, consumer-directed care and elder mistreatment prevention.

Jan Merling, M.A., CTRS, Education Coordinator, is the trainer for "Dementia Dialogues", Prevention of Elder Mistreatment and the Placemat Strength Training Program. Her interests include adult learning and quality of life for older persons.

Candace N. Porter, M.S., PhD, Statistical Research Associate for the Alzheimer's Disease Registry and related projects. Her research interests include AIDS dementia, Alzheimer's disease and related disorders as causes of death, survival analysis, and count data models.

Maggi C. Miller, M.S., PhD, Research Associate/Program Evaluator for the Alzheimer's Disease Registry, provides program coordination and evaluation. Her research interests are in aging, Alzheimer's disease, caregivers of individuals with Alzheimer's disease, and social capital.

Maria Patton, MSW, Director, South Carolina Vulnerable Adult Guardian ad Litem, Pilot Project (SCVAGAL). Her interests include geriatrics, promoting community based services for the elderly and working with the vulnerable population. She is also a certified Geriatric Care Manager.

Angela Gibson, MPH, Research Associate with the Office for the Study of Aging. Her interests include aging, health education for older adults, health behavior change, and chronic disease training. She assists with the HOME CARE + program.

LaToya Reese, B.A., Administrative Assistant, coordinates administrative activity, data entry for all projects, and assists with the HOME CARE + program.

Robert Roscoe, M.A., Research Associate, oversees budgets and provides grant coordinator for all projects.

~ *Affiliated Staff* ~

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Marcia J. Lane, M.P.H., **Data Manager** for the HOME CARE + program. Her research interests include older women's health issues, physical activity, ADRD, medication adherence, elder mistreatment, quality of life in long-term care, and consumer-directed care.

Dorothy Davis, B.A., serves as a **Consultant** for various projects at OSA including Alzheimer's Disease Registry and Community Long Term Care (CLTC) reports.

Dorothy Tudor, provides advise and assistance with storage of historical registry data.

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Sara Wilcox, Ph.D., is Professor, Department of Exercise Science, and Director of Prevention Research Center, Arnold School of Public Health.

~ Office Publications ~

The following is a list of the manuscripts and reports generated by the OSA staff. Reprints of these articles can be obtained from the registry office.

- Schulz, RM, Porter, CN, Lane, MJ, Cornman, CB, Brannon, L. Impact of a Medication Management System on Nursing Home Admission Rate in a Community-Dwelling Nursing Home Eligible Medicaid Population. *American Journal of Geriatric Pharmacotherapy*, 9:1, 69-79, 2010.
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- Anderson LS, Bailey F, Benson WF, Cherry D, Case G, Hendrie HC, Laditka JN, Lappin D, McConnell S, Morrison-Bogorad, Rabins P, Rusinack RL (Author list in Alphabetical Order). *The Health Brain Initiative: A National Public Health Roadmap to Maintaining Cognitive Health*. Centers for Disease Control and Prevention and the Alzheimer's Association. Chicago, IL: Alzheimer's Association, 2007.
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~ *Further Information* ~

This Annual Report is available online at http://osa.sph.sc.edu/alzheimers_registry.html. Any state or local agency may request the registry staff to provide specific data summaries (without identifiers). These requests are handled on an individual basis and will be provided free of charge, as time allows. Contact the registry staff at (803) 777-5337 for further information, or e-mail Carol Cornman at: ccornman@mailbox.sc.edu.